



End of Life Care July 2003

1: Acad Med. 2003 May;78(5):530-7.

Assessing medical students' training in end-of-life communication: a survey of interns at one urban teaching hospital.

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PURPOSE: Although interns are responsible for caring for dying patients, little is known about end-of-life education and training, including communication skills, in U.S. medical schools. This study of three consecutive cohorts of new interns assessed their perceptions of the amount and types of classroom and clinical instructional strategies used during medical school, their self-rated skill and comfort levels in different aspects of end-of-life communication, and the associations between these measures. **METHOD:** A self-administered questionnaire was given to three consecutive cohorts (1996-1998) of incoming interns (n = 162). Measures were self-reported amount and type of education and clinical experience with four end-of-life communication domains (giving bad news, discussing advance directives, discussing prognosis with the patient, and discussing with the patient's family) and self-perceived comfort and skill levels in relation to different types of end-of-life communication. **RESULTS:** A total of 157 interns completed the questionnaire. They reported very little classroom teaching, clinical observation, or clinical experience with end-of-life communication during medical school. They lacked comfort and skill in the end-of-life communication domains that were studied. More reported clinical observation and experience with caring for and communicating with dying patients was associated with greater perceived comfort and skill, while classroom teaching was not. **CONCLUSIONS:** These interns, mostly U.S. medical school graduates (98.7%, n = 155) reported little training and low self-perceived comfort and skill with important elements of end-of-life communication that might contribute to a lack of preparedness to address these issues during their internship. Further research that confirms and explains the underlying reasons for these findings seems warranted.

PMID: 12742792 [PubMed - indexed for MEDLINE]

2: Acad Psychiatry. 2002 Summer;26(2):76-81.

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Management of Terminal Illness: A Medical School-Hospice Partnership Model to Teach Medical Students About End-of-Life Care.

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Physicians are not only called upon to deal with biological, but also with psychosocial issues and concerns in the treatment of the terminally ill. Their training, however, usually does not prepare them to value palliative care, or help them cope with personal feelings about death and possible grief over a patient's loss. The authors describe what one medical school is doing regarding the challenge of preparing medical students to deal more competently and confidently with end-of-life scenarios they will encounter as primary care practitioners in underserved areas of a rural state.

PMID: 12824147 [PubMed]

3: Am Fam Physician. 2003 May 1;67(9):2025-6, 2028.

Do I have to resuscitate this patient against her wishes?

Putnam A.

Lombardi Cancer Center, Palliative Care Program, Georgetown University Medical Center, Washington, DC, USA.

PMID: 12751667 [PubMed - indexed for MEDLINE]

4: Am J Geriatr Cardiol. 2003 Mar-Apr;12(2):110-2.

Proper planning for end-of-life medical care; confronting the near irrelevance of currently used living wills.

Basta LL.

University of South Florida, Tampa, FL, USA.

PMID: 12624581 [PubMed - indexed for MEDLINE]

5: Am J Geriatr Psychiatry. 2003 Jul-Aug;11(4):393-405.

Hope and hopelessness at the end of life.

Sullivan MD.

Received January 2, 2002.

Efforts to improve end-of-life care have been hindered by widespread delays in discussing and initiating this care. The dynamics of hope and hopelessness may be crucial in these delays. The author reviews recent literature concerning hope and hopelessness at the end of life. Modern dying is more prolonged and more shaped by human choice than ever before. Therefore, hope and hopelessness play a more active role in the dying process. Hopelessness is not a simple product of prognosis, but is shaped by state and trait psychological factors. Hope at the end of life can come in various forms: for cure, for survival, for comfort, for dignity, for intimacy, or for salvation. Hopelessness at the end of life is therefore not simply the absence of hope, but attachment to a form of hope that is lost. The concept of anticipatory grief may help us interpret hope and hopelessness at the end of life. Improving end-of-life care will require looking beyond prognosis and preferences to understand the dynamics of hope and hopelessness. To be successful at diversifying hope at the end of life, we must foster the trusting interpersonal environment where this is possible.

PMID: 12837668 [PubMed - in process]

6: Am J Health Syst Pharm. 2003 Jun 15;60(12):1246-50.

Content on end-of-life care in major pharmacy textbooks.

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The quantity and quality of end-of-life-care (EOLC) information in commonly used pharmacy textbooks were studied. EOLC content in each of eight best-selling pharmacy textbooks was assigned to 1 of 13 domains; there were a total of 104 possible domains for all eight books. Every mention of EOLC was given a score of 2 for "helpful content present" or 1 for "minimal content present." The quantity of EOLC content was assessed by tabulating the raw number of entries. The average number of EOLC-related entries per book ranged from 1.0 (ethics) to 27.5 (natural history). Eighty-one domains (78%) had fewer than 10 entries, 66 (63%) had 5 or fewer entries, and 28 (27%) had 1 entry or none. The overall quality of content was low, especially in the domains of spiritual issues, ethics, and context of care. The results were consistent with findings for medicine and nursing textbooks. A review of eight commonly used pharmacy textbooks revealed inadequate coverage of EOLC.

PMID: 12845920 [PubMed - in process]

7: Am J Nurs. 2003 May;103(5):31.

No regrets.

Koch A.

Methodist Medical Center of Illinois in Peoria.

PMID: 12759600 [PubMed - indexed for MEDLINE]

8: Am J Nurs. 2003 May;103(5):52-60; quiz 61.

Improving the quality of end-of-life care.

Virani R, Sofer D.

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Publication Types:

Review

Review, Tutorial

PMID: 12759603 [PubMed - indexed for MEDLINE]

9: BMJ. 2003 Jun 14;326(7402):1335.

'You matter to the last moment of your life'.

Brignall I.

St Ann's Hospice, Manchester.

PMID: 12805195 [PubMed - indexed for MEDLINE]

10: BMJ. 2003 May 31;326(7400):1164.

Only half of Dutch doctors report euthanasia, report says.

Sheldon T.

Publication Types:

News

PMID: 12775601 [PubMed - indexed for MEDLINE]

11: Br J Psychiatry. 2003 Jun;182:548-9; author reply 549.

Comment on:

Br J Psychiatry. 2002 Dec;181:513-9.

How should advance statements be implemented?

Thomas P.

Publication Types:
Comment
Letter

PMID: 12777348 [PubMed - indexed for MEDLINE]

12: Brain Inj. 2003 Jun;17(6):507-23.

Profiles of nursing home residents with traumatic brain injury using the Minimum Data Set.

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OBJECTIVE: To present comprehensive profiles of nursing home residents with TBI at admission. METHODS: Over 12,300 assessments from the Minimum Data Set were analysed to create these profiles. RESULTS: Residents with TBI were overwhelmingly male and averaged 53.1 years of age at admission, with almost 30% being 40 years or younger. They tended to have substantial physical disability and severe cognitive impairment at admission. Compared to other residents at admission, residents with TBI tended to receive more treatments and rehabilitation therapies. CONCLUSION: Caring for residents with TBI presents major challenges for the staff in the traditional nursing home.

PMID: 12745706 [PubMed - indexed for MEDLINE]

13: Bull Med Ethics. 2002 Aug;(180):17-20.

No public health without public death.

Lubbe A.

PMID: 12739535 [PubMed - indexed for MEDLINE]

14: Bull World Health Organ. 2003;81(4):310. Epub 2003 May 16.

Assisted suicide seekers turn to Switzerland.

Avery D.

Publication Types:
News

PMID: 12764503 [PubMed - indexed for MEDLINE]

15: Cancer Nurs. 2003 Jun;26(3):245-51.

When death is imminent: where terminally ill patients with cancer prefer to die and why.

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End-of-life care strives to honor terminally ill patients' preferences regarding the way of dying. Scholars defined one domain of quality of dying and death as dying at the place of one's choice. Despite efforts over more than two decades and more than 40 studies to investigate the influencing factors associated with the place of death for terminally ill patients with cancer, there is a notable lack of empirical data examining the reasons why terminally ill patients with cancer choose a specific setting as their preferred place of death. An exploratory and descriptive study was conducted to explore the preferences of terminally ill patients with cancer for the place of death, to identify the reasons for selecting a preferred place of death, and to examine the importance of dying at a place one prefers. A convenience sample of 180 terminally ill patients with cancer was recruited from four tertiary care hospitals and two home care programs in Connecticut. Nearly 90% of the subjects preferred to die at home. Quality of life, availability and ability of family caregivers, concerns of being a burden to others, long-standing relationships with healthcare providers, and quality of healthcare were the major considerations in decision making regarding the place of death. Terminally ill patients with cancer acknowledged dying at their preferred place of death as highly important. Effective nursing interventions need developing to facilitate death at a place that is in accord with dying patients' preferences.

PMID: 12832958 [PubMed - in process]

16: Chest. 2003 Jul;124(1):392-7.

Dying in the ICU: Perspectives of Family Members.

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OBJECTIVE: To describe the perspectives of family members to the care provided to critically ill patients who died in the ICU. DESIGN: Multicenter, prospective, observational study. SETTING: Six university-affiliated ICUs across Canada. METHODS: Patients who received mechanical ventilation for > 48 h and who died in the ICU were eligible for this study. Three to four weeks after the patient's death, we mailed a validated questionnaire to one selected family member who made at least one visit to the patient in the ICU. We obtained self-rated levels of satisfaction with key aspects of end-of-life care, communication, and decision making, and the overall ICU experience. Main results: Questionnaires were mailed to 413 family members; 256 completed surveys

were returned (response rate, 62.0%). In the final hours before the death of the patient, family members reported that patients were "totally comfortable" (34.8%), "very comfortable" (23.8%), or "mostly comfortable" (32.0%). Family members felt "very supported" (57.0%) and "supported" (30.7%) by the health-care team. Most (82.0%) believed that the patient's life was neither prolonged nor shortened unnecessarily. Most family members (90.4%) preferred some form of shared decision making. Overall, 52% of families rated their satisfaction with care as "excellent," 31% rated care as "very good," 10% as "good," 4% as "fair," and 2% as "poor." Overall satisfaction with end-of-life care was significantly associated with completeness of information received by the family member, respect and compassion shown to patient and family member, and satisfaction with amount or level of health care received. CONCLUSIONS: The majority of families of patients who died in participating ICUs were satisfied with the end-of-life care provided. Adequate communication, good decision making, and respect and compassion shown to both the dying patient and their family are key determinants to family satisfaction.

PMID: 12853551 [PubMed - in process]

17: CMAJ. 2003 Jun 10;168(12):1524.

Compassionate care.

Liben S.

Publication Types:
Letter

PMID: 12796319 [PubMed - indexed for MEDLINE]

18: Conn Med. 2003 May;67(5):283-90; discussion 291-2.

Are living wills useful? In search of a new paradigm.

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Living wills are written by patients to direct physicians and loved ones as to the medical care they want in the event of catastrophic illness that is accompanied by inability to communicate their wishes. We outline recent data suggesting that living wills are poorly understood by patients who have them and that the usefulness of these documents in the clinical arena is extremely limited. Potential solutions for current deficiencies in end-of-life care and decision-making are discussed.

PMID: 12802843 [PubMed - in process]

19: Conn Med. 2003 Jan;67(1):49.

End-of life care.

Coomaraswamy RP.

Publication Types:
Letter

PMID: 12630187 [PubMed - indexed for MEDLINE]

20: Crit Care Med. 2003 Jun;31(6):1711-4.

Comment in:
Crit Care Med. 2003 Jun;31(6):1872-3.

Opinions about surrogate designation: a population survey in France.

Azoulay E, Pochard F, Chevret S, Adrie C, Bollaert PE, Brun F, Dreyfuss D, Garrouste-Orgeas M, Goldgran-Toledano D, Jourdain M, Wolff M, Le Gall JR, Schlemmer B.

The French Famirea Study Group, Intensive Care Unit of the Saint-Louis Teaching Hospital, University Paris 7, Assistance Publique-Hopitaux de Paris, Paris, France.

OBJECTIVE: Many patients go through periods when they are too ill to give consent or to participate in decisions. When this occurs, patient autonomy is best maintained when a surrogate designated by the patient and familiar with his or her values can speak for the patient. The objective of this study was to determine whether people who are not yet ill are ready to accept surrogate designation. Attitudes toward family participation in care were explored also. **DESIGN:** Population survey by telephone. Because refusal of life-sustaining treatment is a dramatic example of patient autonomy, the survey used questions about ICU admission. **SETTING:** General population in France. **SUBJECTS:** Representative random sample of 8000 residents of France aged 18 yrs or more. **INTERVENTIONS:** None. **MAIN OUTCOME MEASURES:** The survey investigated attitudes. **RESULTS:** Most respondents said they would like to designate a surrogate (7205 [90%]) and to have their family share in their care (6691 [84%] for bathing, 5629 [70%] for feeding, and 4139 [52%] for tracheal suctioning) and in decisions about their management (6120 [76%]). Among respondents with a spouse, 79% said they would designate the spouse to speak for them. The attitudes were not influenced by ethnicity, religion or education level. **CONCLUSIONS:** Most people living in France would want a surrogate to represent them should they be incompetent and admitted to an ICU. Primary care physicians should inform their patients about the benefits of discussing illness-related issues among friends and family.

PMID: 12794409 [PubMed - indexed for MEDLINE]

21: Crit Care Med. 2003 Jun;31(6):1872-3.

Comment on:

Crit Care Med. 2003 Jun;31(6):1711-4.

End-of-life captivity of advance directives in the United States: challenges from a French study.

Burck R.

Publication Types:

Comment

Editorial

PMID: 12794439 [PubMed - indexed for MEDLINE]

22: Crit Care Med. 2003 May;31(5 Suppl):S373-8.

Race and the intensive care unit: disparities and preferences for end-of-life care.

Degenholtz HB, Thomas SB, Miller MJ.

Center for Bioethics and Health Law, and Department of Health Policy and Management, University of Pittsburgh, PA 15213, USA.

Publication Types:

Review

Review, Tutorial

PMID: 12771586 [PubMed - indexed for MEDLINE]

23: Crit Care Med. 2003 May;31(5 Suppl):S367-72.

Physician-patient relationship in the intensive care unit: erosion of the sacred trust?

Chaitin E, Stiller R, Jacobs S, Hershl J, Grogen T, Weinberg J.

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With the advent of the increasing technology and multispecialty medicine, the strong relationship or "sacred trust" between patient and family physician has gradually eroded. Various subspecialists are now entrusted with patient care at different phases of evaluation and treatment. Because of the transient nature of these physician-patient interactions, a strong bond is often not established before critical decisions must be made concerning ongoing patient care. As a result, multiple members of the different healthcare teams (the care cooperative) may be confronted with addressing end-of-life discussions, which in the past was the responsibility of the primary physician. Because of this need

to move into a previously viewed private territory, communication conflicts may arise between members of the healthcare team. In an effort to understand and deal with observed recurrent problems that occurred when patient care was transferred between specialty care teams, our institution has addressed communication conflicts that arise in the care of oncology patients transferred to the intensive care unit. Our goal has been to initiate and maintain a dialog to avoid misunderstandings and to reduce anxiety between members of the intensivist and oncology services. To this end, we have addressed the various pitfalls that come with the transition from the traditional physician-patient relationship to the more fluid and comprehensive care-cooperative mode. We believe this approach to be useful in improving communication between healthcare providers in the multispecialty care setting, which will ultimately enhance the quality of patient care.

Publication Types:

Review

Review, Tutorial

PMID: 12771585 [PubMed - indexed for MEDLINE]

24: Crit Care Med. 2003 May;31(5 Suppl):S354-7.

Cultural differences at the end of life.

Levin PD, Sprung CL.

Department of Anesthesiology and Critical Care Medicine, Hadassah Hebrew University Medical Center, Jerusalem, Israel.

Publication Types:

Review

Review, Tutorial

PMID: 12771582 [PubMed - indexed for MEDLINE]

25: Crit Care Med. 2003 May;31(5):1543-50.

Comment in:

Crit Care Med. 2003 May;31(5):1593-5.

Do-not-resuscitate order after 25 years.

Burns JP, Edwards J, Johnson J, Cassem NH, Truog RD.

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BACKGROUND: In 1976, the first hospital policies on orders not to resuscitate were published in the medical literature. Since that time, the concept has continued to evolve and evoke much debate. Indeed, few initials in medicine today evoke as much symbolism or controversy as the Do-Not-Resuscitate (DNR) order. **OBJECTIVE:** To review the development, implementation, and present

standing of the DNR order. DESIGN: Review article. MAIN RESULTS: The DNR order concept brought an open decision-making framework to the resuscitation decision and did much to put appropriate restraint on the universal application of cardiopulmonary resuscitation for the dying patient. Yet, even today, many of the early concerns remain. CONCLUSIONS: After 25 yrs of DNR orders, it remains reasonable to presume consent and attempt resuscitation for people who suffer an unexpected cardiopulmonary arrest or for whom resuscitation may have physiologic effect and for whom no information is available at the time as to their wishes (or those of their surrogate). However, it is not reasonable to continue to rely on such a presumption without promptly and actively seeking to clarify the patient's (or surrogate's) wishes. The DNR order, then, remains an inducement to seek the informed patient's directive.

Publication Types:

Review

Review, Tutorial

PMID: 12771631 [PubMed - indexed for MEDLINE]

26: Crit Care Med. 2003 May;31(5):1551-7; discussion 1557-9.

Corrected and republished from:

Crit Care Med. 2003 Apr;31(4):1263-70.

Surgeons, intensivists, and the covenant of care: administrative models and values affecting care at the end of life--Updated.

Cassell J, Buchman TG, Streat S, Stewart RM.

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CONTEXT: End-of-life care remains a challenging and complex activity in critical care units. There is little information concerning the influence of administrative models of care delivery on end-of-life care. OBJECTIVE: To compare and contrast end-of-life care delivery in intensive care units using "semiclosed," "open," and "closed" administrative models. DESIGN: Ethnographic study of three critical care units. SETTING: University hospitals in the United States and New Zealand. SUBJECTS: Approximately 600 physicians, nurses, allied health personnel, patients, family members, and friends. MEASUREMENTS AND MAIN RESULTS: Ethnographic observations were made at three sites for 75, 3, and 10 wks, respectively. Eighty end-of-life care episodes were observed. The interactions among care personnel and families varied according to the administrative model, depending on whether surgeons or intensivists had primary patient responsibility. This led to differential timing on the shift from "cure" to "comfort," and differential decision-making power for families. CONCLUSIONS: End-of-life care varies according to the administrative model. When surgeons have primary responsibility for the patient, the most important goal is defeating death. When intensivists have sole patient responsibility, scarce resources are considered and quality of life is a significant variable. Discussions about improving the way end-of-life decisions are carried out in intensive care units rarely consider the administrative models and personal, professional, and national values affecting such decisions. To improve care at

the end of life, we must critically examine these features.

Publication Types:

Corrected and Republished Article

PMID: 12771632 [PubMed - indexed for MEDLINE]

27: Crit Care Med. 2003 May;31(5):1593-5.

Comment on:

Crit Care Med. 2003 May;31(5):1543-50.

Do not resuscitate: ordering nonassault and charting patients' decisions to forgo cardiopulmonary resuscitation.

Veatch RM.

Publication Types:

Comment
Editorial

PMID: 12771647 [PubMed - indexed for MEDLINE]

28: Curr Cardiol Rep. 2003 May;5(3):223-8.

Management of heart failure in the elderly.

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Chronic heart failure is an epidemic disorder in the elderly population. The frequent coexistence of comorbid illnesses and psychosocial issues in older persons often makes diagnosis and management difficult. Physicians must be aware of the current diagnostic modalities and proven therapies as they apply to elderly patients in order to achieve optimal outcomes. This article reviews new approaches to the diagnosis of heart failure, and discusses the latest evidence for both pharmacologic and nonpharmacologic treatment for this condition. Multidisciplinary strategies for the management of heart failure and end-of-life care are also briefly discussed.

Publication Types:

Review
Review, Tutorial

PMID: 12691641 [PubMed - indexed for MEDLINE]

29: Death Stud. 2003 Jul;27(6):501-18.

Physician-assisted suicide in Oregon: what are the key factors?

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Oregon's Death with Dignity Act has been operative since late 1997. The substantial national and international interest in Oregon's law makes it important to document any possible trends in the characteristics of persons who use the law. To do this, the present article examines previously reported data from various sources and places them within the context of the end-of-life decisions more generally. The Oregon data demonstrate that, regardless of the care received, a very small percentage of terminally ill Oregonians seem determined to request a lethal medication so that they may control the manner and timing of their death. College graduates and divorced persons are substantially more likely to use physician-assisted suicide to end their lives than are other persons. Control and autonomy appear to be the primary issues associated with taking legally prescribed medication to hasten one's death. A better understanding of the influence that a patient's marital status, education level, and desire for control may have on her or his ability to cope with, and make decisions related to, a terminal illness may allow health care professionals to better care for dying patients.

PMID: 12814130 [PubMed - indexed for MEDLINE]

30: Ethics Behav. 2002;12(3):205-22.

Confidentiality in end-of-life and after-death situations.

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Confidentiality is one of the foundations on which psychotherapy is built. Limitations on confidentiality in the therapeutic process have been explained and explored by many authors and organizations. However, controversy and confusion continue to exist with regard to the limitations on confidentiality in situations where clients are considering their options at the end of life and after a client has died. This article review these 2 areas and provides some suggestions for future research.

PMID: 12653121 [PubMed - indexed for MEDLINE]

31: Gerontologist. 2003 Jun;43(3):309-17.

Advance care planning in nursing homes: correlates of capacity and possession of advance directives.

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PURPOSE: The identification of nursing home residents who can continue to participate in advance care planning about end-of-life care is a critical clinical and bioethical issue. This study uses high quality observational research to identify correlates of advance care planning in nursing homes, including objective measurement of capacity. **DESIGN AND METHODS:** The authors used cross-sectional, cohort study between 1997 and 1999. Seventy-eight residents (M age = 83.97, SD = 8.2) and their proxies (M age = 59.23, SD = 11.77) were included across five nursing homes. The authors obtained data via chart review, proxy interviews, resident assessments, survey completion by certified nursing assistants, and direct observation of residents' daily behaviors. **RESULTS:** Capacity assessments revealed that most residents could state a simple treatment preference (82.4%), but a sizable number did not retain capacity to understand treatment alternatives or appreciate the consequences of their choice. Global cognitive ability (Mini-Mental State Examination score) was related to understanding and appreciation. When the authors removed the effects of global cognitive ability, understanding and appreciation were related to time spent by residents in verbal interaction with others. Residents were more likely to possess advance directives when proxies possessed advance directives, proxies were less religious, and residents were socially engaged. **IMPLICATIONS:** Assessment of proxy beliefs and direct determination of residents' decisional capacity and social engagement may help nursing home staff identify families who may participate in advance planning for end-of-life medical care. Measures of global cognitive ability offer limited information about resident capacity for decision making. Decisional capacity assessments should enhance the verbal ability of individuals with dementia by reducing reliance on memory in the assessment process. Interventions to engage residents and families in structured discussions for end-of-life planning are needed.

PMID: 12810894 [PubMed - in process]

32: Gerontologist. 2003 Jun;43(3):302-8.

Differences in presenting advance directives in the chart, in the minimum data set, and through the staffs perceptions.

Cohen-Mansfield J, Libin A, Lipson S.

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PURPOSE: Decisions concerning end-of-life care depend on information contained in advance directives that are documented in residents' charts in the nursing home. The availability of that information depends on the quality of the chart and on the location of the information in the chart. No research was found that compared directives by the manner in which they are collected and summarized in the chart. The goal of the proposed study was to clarify how advance directives are summarized in the patient's record and to clarify how physicians perceive the same advance directives and formal orders. **DESIGN AND METHODS:** The study

involved 122 elderly persons who reside in one large (587 beds) nursing home. The authors collected data regarding the advance directives from three sources-Minimum Data Set (MDS), the front cover of the resident's chart, and from inside the chart. RESULTS: The rates of documented advance directives found in this study are higher than those reported in the literature. Agreement rates between sources varied as a function of which sources were compared, as well as on the basis of which directive was examined. More specifically, the authors found higher rates of agreement between the information inside the chart and on the cover of the chart than between the MDS and the other two sources. IMPLICATIONS: The reasons for discrepancies may lie in the different functions and procedures pertaining to these source documents.

PMID: 12810893 [PubMed - in process]

33: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S18-9.

Pictures of persons and the good of hospice care.

Nelson HL.

Department of Philosophy, Center for Ethics and Humanities in the Life Sciences,
Michigan State University, USA.

PMID: 12762187 [PubMed - indexed for MEDLINE]

34: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S45-7.

Is discontinuity in palliative care a culpable act of omission?

Ryndes T, Emanuel L.

National Hospice Work Group, San Diego Hospice, USA.

PMID: 12762192 [PubMed - indexed for MEDLINE]

35: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S40-1.

Rediscovering community at the core of the human condition and social covenant.

Byock I.

University of Montana, USA.

PMID: 12762191 [PubMed - indexed for MEDLINE]

36: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S30-2.

The relevance of public health in improving access to end of life care.

D'Onofrio C, Ryndes T.

School of Public Health, University of California, Berkeley, USA.

PMID: 12762190 [PubMed - indexed for MEDLINE]

37: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S24-6.

Hospice and Alzheimer disease: a study in access and simple justice.

Jennings B.

PMID: 12762189 [PubMed - indexed for MEDLINE]

38: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S22-3.

What the people would want if they knew more about it: a case for the social marketing of hospice care.

Stanley JM.

Lawrence University, Appleton, Wis., USA.

PMID: 12762188 [PubMed - indexed for MEDLINE]

39: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S14-5.

Health care justice and hospice care.

Sulmasy DP.

St. Vincent's Hospital, Manhattan, USA.

PMID: 12762186 [PubMed - indexed for MEDLINE]

40: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S8-9.

Caregiving at the end of life.

Connor S, Adams J.

National Hospice and Palliative Care Organization, Alexandria, Va., USA.

PMID: 12762185 [PubMed - indexed for MEDLINE]

41: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S3-7, S9-13, S15-21 passim.

Access to hospice care. Expanding boundaries, overcoming barriers.

Jennings B, Ryndes T, D'Onofrio C, Baily MA.

National Hospice Work Group, San Diego Hospice, USA.

PMID: 12762184 [PubMed - indexed for MEDLINE]

42: Hawaii Med J. 2003 May;62(5):100-3.

Perceptions of a required hospice experience: a comparison of first- and fourth-year medical students.

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As more attention is focused on the need to improve end-of-life care, medical schools are expanding curricula in this area. This paper presents information about a 12-week, 60-hour hospice unit required for first-year medical students between 1989 and 2001, along with a comparison of first- and fourth-year students' perceptions of this unit. Surveyed in summer of 2001 were 111 individuals who had completed the unit: 59 students who had completed the hospice unit in the 2000-01 academic year and 52 graduating students who had completed the hospice unit in the 1997-98 academic year. The survey tapped perceptions of usefulness of the unit, comfort with end-of-life-care knowledge and skills, and suggestions for improvement. Ninety percent of graduating students rated the hospice experience as personally valuable and 81% acceded its important for medical education, compared to 69% and 65% of first-year students, respectively. Almost all felt that the hospice unit was a useful experience for them as future clinicians. However, there were few differences in comfort with end-of-life skills between the two classes, e.g., almost 90% felt comfortable listening to patients; about 50% felt comfortable with their knowledge of grief/bereavement, symptom control, physical needs and psychosocial needs; and only 25% felt comfortable discussing a patient's terminal illness with the patient and family. The majority of students felt the unit should remain a first-year requirement, but wanted more opportunities to attend dying patients, work with physician role models, and reflect on their experience with death and its meaning.

PMID: 12806789 [PubMed - in process]

43: Health Commun. 2003;15(2):219-26.

The communication of palliative care for the elderly cancer patient.

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Palliative care (PC) is often recommended by physicians for their elderly patients who are terminally ill. In contrast to hospice care, which precludes the use of any curative treatment at life's end stages, PC seeks primarily to comfort patients and to keep them pain free, yet it does not necessarily preclude medical treatment. It does seek to attend to patients' physical as well as psychological, emotional, spiritual, and existential needs in an attempt to enhance overall quality of life. A review of current literature in PC for oncology patients, elderly and otherwise, reveals a curious irony: Although PC plausibly entails a holistic, patient-centered approach to health care, much of the research on PC and, apparently, many of the practices in PC focus almost exclusively on the biomedical approach to patient care, particularly in regard to pain and symptom management. Furthermore, few methods in PC research incorporate patients' narratives and lived experiences in the final stages of their lives. We argue that a holistic, patient-centered approach must guide research in PC, including the treatment of elderly patients as "active interpreters, managers, and creators of the meaning of their health and illness" (Vanderford, Jenks, & Sharf, 1997, p.14) and of the meaning of their lives.

PMID: 12742772 [PubMed - indexed for MEDLINE]

44: J Aging Health. 2003 May;15(2):409-29.

Thinking ahead: factors associated with executing advance directives.

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This article examines why older adults do or do not execute advance directives. METHODS. Secondary data analysis was conducted on data from the Charlotte County (Florida) Healthy Aging Study, on 451 adults who were relatively healthy and affluent. Exploratory logistic regressions were conducted on the probability that respondents had executed advance directives. RESULTS. Findings indicated that increasing age and higher income were the most consistent indicators of having executed an advance directive. Also, individuals reporting taking more prescription medications were more likely to have all the advance directives, except the durable power of attorney for health care. Reporting more negative life events was predictive of having executed the durable power of attorney for health care. DISCUSSION. These findings suggest that in addition to awareness of advance directives, demographic, health, and situational factors may affect the willingness of older adults to execute advance directives. Further research should examine other, more representative, samples to confirm these findings.

PMID: 12795282 [PubMed - indexed for MEDLINE]

45: J Am Coll Surg. 2003 Jun;196(6):977-83.

Families' perceptions of surgical intensive care.

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PMID: 12788436 [PubMed - indexed for MEDLINE]

46: J Am Geriatr Soc. 2003 Jul;51(7):961-9.

Life-sustaining treatments: what do physicians want and do they express their wishes to others?

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OBJECTIVES: To assess whether older physicians have discussed their preferences for medical care at the end of life with their physicians, whether they have established an advance directive, and what life-sustaining treatment they wish in the event of incapacity to make these decisions for themselves. **DESIGN:** Mailed survey to a cohort of physicians. **SETTING:** Physicians who were medical students at the Johns Hopkins University in graduating classes from 1946 to 1964. **PARTICIPANTS:** Physicians who completed the advance directive questionnaire (mean age 68). **MEASUREMENTS:** Questionnaires were sent out to known surviving physicians of the Precursors Study, an on-going study that began in 1946, asking physicians about their preferences for life-sustaining treatments. **RESULTS:** Of 999 physicians who were sent the survey, 765 (77%) responded. Forty-six percent of the physicians felt that their own doctors were unaware of their treatment preferences or were not sure, and of these respondents, 59% had no intention of discussing their wishes with their doctors within the next year. In contrast, 89% thought their families were probably or definitely aware of their preferences. Sixty-four percent reported that they had established an advance directive. Compared with physicians without advance directives, physicians who established an advance directive were more likely to believe that their doctors (odds ratio (OR) = 3.42, 95% confidence interval (CI) = 2.49-4.69) or family members (OR = 9.58, 95% CI = 5.33-17.23) were aware of their preferences for end-of-life care and were more likely to refuse treatments than those without advance directives. **CONCLUSION:** This survey of physicians calls attention to the gap between preferences for medical care at the end of life and expressing wishes to others through discussion and advance directives, even among physicians.

PMID: 12834516 [PubMed - in process]

47: J Am Med Dir Assoc. 2003 Jan-Feb;4(1):23-6.

Staff perceptions of end-of-life care in long-term care.

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OBJECTIVE: Although residential care/assisted living facilities and nursing homes have increasingly become a significant site of death for older Americans, little is known about staff perceptions of end-of-life care, perceived need for improvement in care, and differences by type of setting. **DESIGN, SETTING, AND PARTICIPANTS:** Ninety-nine staff provided their perceptions of end-of-life care for 99 decedents from 74 residential care/assisted living facilities and nursing homes in four states as part of a larger cohort study. Staff were interviewed retrospectively regarding care provided during residents' last month of life. **MEASUREMENTS:** Staff reported on 11 areas of end-of-life care, describing the importance of each area and the level of improvement they felt was indicated. Weighted "need for change" scores were calculated as the product of perceived importance and need for improvement. **RESULTS:** Both residential care/assisted living and nursing home staff reported a need for more staff education and nursing assistant time, as well as more use of volunteers. The two lowest ranked items for both facility types were involvement of hospice and encouragement for staff to attend funeral services. Nursing home staff perceived a greater need for improvement than residential care/assisted living staff in all 11 areas. **CONCLUSION:** Results underscore the staffing demands of end-of-life care across facility types, and staff desires to be able to provide quality care throughout the dying process.

PMID: 12807593 [PubMed - in process]

48: J Am Med Dir Assoc. 2003 Jan-Feb;4(1):16-22.

A profile of residents admitted to long-term care facilities for end-of-life care.

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INTRODUCTION: Permanent placement in a Long-Term-Care (LTC) facility following hospitalization or when staying at home is no longer a viable option is the reality for a growing number of Americans. When death is imminent, the specialized knowledge and skill of the hospice team is required and accepted as an important component of end-of-life (EOL) care. The provision of appropriate care at the EOL is contingent on accurate identification of those residents who are approaching the final stage of life. This study describes the prevalence, profile, and survivorship of residents admitted to LTC facilities, using the Minimum Data Set (MDS) designation of being at the EOL. **METHODS:** A descriptive, correlational, retrospective cohort design was used to analyze all residents admitted to certified LTC facilities with hospice contracts in Missouri in 1999.

Variables for analysis were selected from the MDS items that are clinically relevant for those residents at the EOL, for example, pain, incontinence, skin condition, activities of daily living (ADLs), depression, and weight loss. In addition, items regarding advance directives, use of special treatments, and diagnoses were selected because they are important to the care of residents at the EOL. RESULTS: Of 492 eligible facilities, 159 were confirmed as providing hospice care. Of 9615 admissions to these facilities, 432 (4.5%) met the EOL care definition; half of these were receiving specialist hospice care. The EOL residents were distinguishable in terms of symptoms. Median survival time for EOL admissions was 33 days. At 6 months, only 17% of EOL admissions remained in the facility. CONCLUSIONS: Residents designated as EOL who are admitted to LTC are a distinct group from other new residents, with identifiable needs requiring specialist attention. Accurate recognition that EOL is imminent is required for the development of appropriate strategies and resources for care.

PMID: 12807592 [PubMed - in process]

49: J Am Med Dir Assoc. 2002 Mar-Apr;3(2):57-65.

End-of-Life Care in Dementia: A Review of Problems, Prospects, and Solutions in Practice.

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The purpose of this literature review was to assess the current state of affairs in end-of-life care for persons with dementia, to identify barriers to the provision of high-quality care, and to describe exemplary programs that have discovered ways to overcome these barriers. The literature reviewed included English-language articles published since 1990, obtained by searches of Medline, presentations at meetings and conferences, and the Internet. Barriers to quality terminal dementia care identified by this review include: (1) measurement issues regarding quality of carequality of life, (2) inappropriate interventions stemming from lack or disregard of advance directives, cost considerations, healthcare system factors, and caregiver factors, (3) poor symptom management involving both professional and family caregivers, and (4) current health policy formulated by federal or state governments, insurance companies, and health maintenance organization. High-quality care for persons with dementia at the end of life is possible and is currently being provided in some settings. Further research into areas identified in this review is necessary if the quality of care being provided to this population is to improve.

PMID: 12807540 [PubMed]

50: J Am Med Dir Assoc. 2002 Mar-Apr;3(2):51-6.

Challenges in pain management among persons with AIDS in a long-term-care

facility.

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OBJECTIVE: Opiate-resistant pain has been studied in cancer for many years; however, its existence in end-stage acquired immunodeficiency syndrome (AIDS) has captured little attention. This paper examines the existence, prevalence, and characteristics of opiate-resistant pain among persons with AIDS receiving end of life care at Bailey-Boushay House, an AIDS-skilled nursing facility in Seattle, WA. **Methods:** A retrospective chart review of consecutive discharges during 1996 to 1999 examined patients near the end of life with advanced AIDS who had used opioid patient-controlled analgesia (PCA) for pain relief. The patients were divided into a control group (n = 97) and an opiate-resistant group (ongoing, severe pain with morphine use of greater than 100 mg/hr in an alert patient with no response to doubling doses, n = 12). The two groups were compared on the basis of current diagnosis of depression, history of injection drug abuse, peripheral neuropathy, or central nervous system involvement. **RESULTS:** Out of a total of 740 AIDS admissions during the study period, 226 patients were admitted for terminal care. Of these, 109 utilized a PCA for pain control for at least a day before death. Twelve (1.6% of all admissions, 5% of terminal patients, 11% of PCA users) experienced opiate-resistant pain. No associations with injection drug abuse, central nervous system involvement, depression, or peripheral neuropathy were found. **CONCLUSIONS:** Opiate-resistant pain is rare and can be relieved by aggressive use of adjuvants for pain treatment. There are no distinguishing characteristics that are predictive of this pain syndrome among AIDS patients near the end of life. The recognition of, prompt attention to, opiate-resistant pain remains a challenge for medical providers.

PMID: 12807539 [PubMed]

51: J Am Med Dir Assoc. 2000 Nov-Dec;1(6):284-8.

Ethics Issues: Using Basic Management Techniques to Improve End-of-Life Care: Part III.

Levenson SA, Feinsod F.

PMID: 12812615 [PubMed]

52: J Am Med Dir Assoc. 2000 Sep-Oct;1(5):228-31.

Ethics Issues: Using Basic Management Techniques to Improve End-of-Life Care: Part II.

Levenson SA, Feinsod F.

PMID: 12812625 [PubMed]

53: J Am Med Dir Assoc. 2000 Jul-Aug;1(4):182-6.

Using Basic Management Techniques to Improve End-of-life Care.

Levenson SA, Feinsod F.

PMID: 12816559 [PubMed]

54: J Contin Educ Nurs. 2003 May-Jun;34(3):122-7.

Nurses' needs for education on cancer and end-of-life care.

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BACKGROUND: Changes in cancer and end-of-life care require frequent assessment of educational needs of nurses. METHODS: The Nurse Oncology Education Program surveyed a random sample of Texas registered nurses about their continuing education practices, level of knowledge, and educational needs. RESULTS: The 352 nurses responding to the survey primarily obtained continuing education from workshops, inservice education, and independent studies citing cost, location, content, and length of course as influencing factors. Their cancer educational needs included clinical trials, genetics, complementary therapies, and pain management. Nurses' perceptions of end-of-life needs were for physical needs, "what to expect" concerns, and transition to palliative care. CONCLUSION: These findings provide specific direction for future continuing education programs about cancer and end-of-life issues for nurses.

PMID: 12772811 [PubMed - indexed for MEDLINE]

55: J Crit Care. 2003 Mar;18(1):3-10.

The seriously ill hospitalized patient: preferred role in end-of-life decision making?

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PURPOSE: The objective of this study was to further our understanding of the decision-making process near the end of life. Specifically, we ascertained the seriously ill patients' preferred role in the decision-making process, what factors were associated with this role, and how this stated preference related to physicians' perception of preferred role. MATERIALS AND METHODS: Prospective cohort study of hospitalized patients with end-stage congestive heart disease, chronic pulmonary disease, cirrhosis, or metastatic cancer. Eligible patients

were interviewed to ascertain their personal views on end-of-life decision making, desired role, and level of symptoms experienced. RESULTS: A total of 135 patients were enrolled in this study. The majority of patients (103, 76%) had thought about end-of-life issues although only 48 (36%) had discussed them with their doctor in the hospital. With respect to preferred role in decision making, in the scenario of a competent patient, 14 (10%) preferred to leave all decisions to the doctor, 12 (9%) preferred that the doctor make the final decision after considering their opinion, 43 (32%) preferred that the doctor shared responsibility with them to make the decision, 32 (24%) patients preferred to make the final decision after considering the doctor's opinion, 21 (16%) preferred to make the treatment decision alone, and 13 (10%) did not answer. Physicians were not able to accurately predict patient's preferred role nor could the variability in patient choice be accounted for by demographic or symptom covariates. CONCLUSION: Seriously ill hospitalized patients desire to discuss end-of-life issues with their physicians but their preferred role in decision making is variable and difficult to predict. Copyright 2003 Elsevier, Inc. All rights reserved.

PMID: 12640606 [PubMed - indexed for MEDLINE]

56: J Infus Nurs. 2003 May-Jun;26(3):144-52.

Parenteral hydration and nutrition in the geriatric patient: clinical and ethical issues.

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A common ethical and legal issue in elder care involves the decision to withhold or withdraw parenteral hydration and nutrition (PHN) at the end of life and in the terminal stage of dementia. The aging of the population will impact the frequency with which nurses face this situation in their practices and with their families. The ethical, legal, and clinical issues involving PHN discussed in this article will assist the nurse in his or her practice.

Publication Types:

Review

Review, Tutorial

PMID: 12792372 [PubMed - indexed for MEDLINE]

57: J Pain Symptom Manage. 2003 May;25(5):438-43.

Antimicrobial use in patients with advanced cancer receiving hospice care.

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Patients with advanced cancer receiving hospice and palliative care are highly susceptible to infections. The decision whether to treat an active or suspected infection in end-of-life care may be difficult. In order to develop guidelines for the use of antimicrobials (antibiotics and antifungals) in palliative care, we discussed antimicrobial options with 255 patients with advanced cancer at the time they entered a community-based hospice and palliative care program. We subsequently documented the use and effectiveness of the antimicrobials employed during the palliative care period. Most patients (79.2%) chose either no antimicrobials or symptomatic use only. Choices were influenced by age, the desire for symptom control, life-prolongation issues, and the condition of the patient. After admission, 117 patients had a total of 129 infections, with the most common sites being urinary tract, respiratory tract, mouth/pharynx, and skin/subcutaneous tissues. The use of antimicrobials controlled symptoms in the majority of the urinary tract infections, but were less effective in controlling symptoms in the other sites of infection. Survival was not affected by the patients' choice of whether to use antimicrobials, the prevalence of infections, or the actual use of antimicrobials. Symptom control may be the major indication for antimicrobial use for patients receiving hospice and palliative care.

PMID: 12727041 [PubMed - indexed for MEDLINE]

58: J Palliat Care. 2003 Spring;19(1):5-6.

Comment on:

J Palliat Care. 2003 Spring;19(1):9-14.

Research at the interface of palliative care and geriatrics.

Sachs GA.

Publication Types:

Comment

Editorial

PMID: 12710108 [PubMed - indexed for MEDLINE]

59: J Palliat Care. 2003 Spring;19(1):49-53.

Hospice use by older women dying with breast cancer between 1991 and 1996.

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The purpose of this study was to assess the use of hospice by women dying with breast cancer as a function of time period, geographic area, and patient characteristics. We used data from the linked Surveillance, Epidemiology, and End Results (SEER)-Medicare database to study hospice care use in the United States in women aged 65 and older, diagnosed with breast cancer from 1986 to

1996, who died from 1991 to 1996. Of the 25,161 women who met those criteria, 5,198 (20.7%) were enrolled in hospice before they died. The rate of hospice use in this population increased from 11.5% in 1991 to 27.1% in 1996. Use of hospice care was inversely related to age and was higher among those who were married. There were no differences in use by ethnicity. Rates of use varied significantly by geographic area. Future research should further examine why rates of hospice use differ by geographic area and certain patient characteristics.

PMID: 12710115 [PubMed - indexed for MEDLINE]

60: J Palliat Care. 2003 Spring;19(1):36-42.

Mapping the journey: family carers' perceptions of issues related to end-stage care of individuals with muscular dystrophy or motor neurone disease.

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Progress in medical technology and treatment has resulted in more people with neurodegenerative conditions surviving for longer periods of time. This increased lifespan means that these individuals have a longer period of dependency on others, with a heightened need to maintain quality of life for both the individual and the family. Our paper reports on the findings of a study involving in-depth interviews with 16 carers to determine their perceived needs during the final stage of caring for someone with muscular dystrophy (MD) or motor neurone disease. Results suggest that the palliative care model has much to offer individuals with degenerative neuromuscular conditions and their families, but it is not yet recognized as an important part of care for young people with MD. Three major themes emerged in the analysis: reactions and responses, health system crossing points, reaching forward.

PMID: 12710113 [PubMed - indexed for MEDLINE]

61: J Palliat Care. 2003 Spring;19(1):15-26.

The impact on families of a children's hospice program.

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Pediatric hospice is a relatively new development in the field of hospice care. This article reports on an evaluation project that examined the effect of the Canuck Place children's hospice program on the families it served during its first two and a half years of operation. Using the principles of participatory action research, data were collected from individual interviews, focus groups, and mail-out surveys of families who used the program. Sixteen categories of hospice program effect were found to summarize how families regarded, used, and

assessed their experiences. Families overwhelmingly endorsed the Canuck Place program. They also provided helpful suggestions for improvement and growth, particularly during the program's formative years. Recommendations are made with a view to promoting and solidifying the ongoing success of the Canuck Place program, as well as of children's hospice programs in general.

PMID: 12710111 [PubMed - indexed for MEDLINE]

62: J Palliat Med. 2003 Apr;6(2):311-3.

Expanding the realm of the possible.

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PMID: 12854951 [PubMed - in process]

63: J Palliat Med. 2003 Apr;6(2):257-64.

The invisible dimension: abuse in palliative care families.

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The family as the unit of care underpins the philosophy and practice of palliative care. Through this model of service delivery, palliative care professionals attempt to provide holistic, quality end-of-life care to terminally ill patients and their families. The research on palliative care families to date, however, constructs the family unit as functional, articulate, cohesive and, thus, able to adapt to the impact of a terminal diagnosis, albeit with professional intervention if required. This notion of the family as monolithic and unproblematic masks the existence of family issues that have the potential to impact negatively on the care that patients receive, and thus constrain the palliative health professional in facilitating quality end-of-life care. Through a review of current literature, this paper identifies such an issue--that of abusive family relationships--which has been hitherto neglected in palliative care research. It is suggested that the issue of abusive family relationships needs to be identified and responded to at some level if the goal of providing holistic care and facilitating a "good death" for all terminally ill people receiving palliative care is to be achieved. The continued invisibility of this issue does not resolve the problem of abuse and could result in the implementation or continuation of practices that may in fact be damaging.

PMID: 12854943 [PubMed - in process]

64: J Palliat Med. 2003 Apr;6(2):205-13.

Nursing home physician educational intervention improves end-of-life outcomes.

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CONTEXT: Nursing homes are the setting for one of five deaths in the United States. Unfortunately these deaths are often accompanied by pain and symptoms of discomfort. OBJECTIVE: To determine if an educational intervention designed for nursing home physicians improves the quality of dying for nursing home residents. DESIGN: Prospective measurement of changes in end-of-life medical care indicators. INTERVENTION: Half-day adult educational outreach program, including audit and feedback, targeted at opinion leaders, and quality improvement suggestions. SETTING: Five geographically diverse Maryland skilled nursing facilities with a total of 654 beds. PARTICIPANTS: The terminal care delivered by 61 physicians who cared for 203 dying residents in the 5 facilities was reviewed. An intervention was targeted to medical directors and those physicians with the majority of patients. Twelve physicians participated in the educational program. MAIN OUTCOME MEASURES: Chart documentation of recognition of possible death, presence of advance directives, pain control, analgesics used, dyspnea control, control of uncomfortable symptoms during the dying process, documented hygiene, documented bereavement support, and total patient comfort. RESULTS: The four nursing facilities that completed the intervention all had significant improvements in end-of-life care outcomes ($p < 0.001$, χ^2). No statistically significant changes were found in any measure in the cohort nursing facility that did not complete the intervention. When we compared residents with hospice services to those without, we found significant increases in documentation of better hygiene, bereavement support, and total patient comfort ($p < 0.001$, χ^2 for each). CONCLUSIONS: Important terminal care outcomes can be significantly improved by targeting key nursing home physicians with an adult educational program that includes audit and feedback, and quality improvement suggestions.

PMID: 12854937 [PubMed - in process]

65: J Palliat Med. 2003 Apr;6(2):315-20.

Palliative Excellence in Alzheimer Care Efforts (PEACE): a program description.

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Hospice is the standard method for providing quality end-of-life care in the United States. However, studies reveal that persons with dementia are infrequently referred to hospice, that barriers exist to increasing hospice

utilization in this population, and that patients with dementia would benefit from hospice or hospice-like services earlier in the disease course. The Palliative Excellence in Alzheimer Care Efforts (PEACE) program responds to these deficiencies, striving to improve end-of-life care of persons with dementia and to integrate palliative care into the primary care of patients with dementia throughout the course of the illness. The PEACE program is a disease management model for dementia that incorporates advance planning, patient-centered care, family support, and a palliative care focus from the diagnosis of dementia through its terminal stages. PEACE is coordinated through the primary care geriatrics practice of the University of Chicago. Patients and caregivers are interviewed every 6 months for 2 years, and a postdeath interview is conducted with caregivers. These interviews assess care domains important for the optimal care of persons with dementia and their caregivers. A nurse coordinator reviews interviews and provides feedback to physicians, facilitating enhanced individual care and continuous quality improvement for the practice. Initial feedback suggests patients have adequate pain control, satisfaction with quality of care, appropriate attention to prior stated wishes, and death occurring in the patient's location of choice. Families voiced similar high marks regarding quality of care. This program demonstrates an innovative model of providing quality palliative care for dementia patients and their caregivers.

PMID: 12854952 [PubMed - in process]

66: JAMA. 2003 Jul 2;290(1):73-80.

Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment.

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CONTEXT: Empiric data and expert opinion suggest that use of feeding tubes is not beneficial for older persons with advanced dementia. Previous research has shown a 10-fold variation in this practice across the United States. OBJECTIVE: To identify the facility and resident characteristics associated with feeding tube use among US nursing homes residents with severe cognitive impairment. DESIGN, SETTING, AND PARTICIPANTS: Cross-sectional study of all residents with advanced cognitive impairment who had Minimum Data Set assessments within 60 days of April 1, 1999, (N = 186,835) and who resided in Medicare- or Medicaid-certified US nursing homes. Main Outcomes Measures Facility and resident characteristics described in the 1999 On-line Survey Certification of Automated Records and the 1999 Minimum Data Set. Multivariate analysis using generalized estimating equations determined the facility and resident factors independently associated with feeding tube use. RESULTS: Thirty-four percent of residents with advanced cognitive impairment had feeding tubes (N = 63,101). Resident characteristics associated with a greater likelihood of feeding tube use included younger age, nonwhite race, male sex, divorced marital status, lack of advance directives, a recent decline in functional status, and no diagnosis of Alzheimer disease. Controlling for these patient factors, residents living in

facilities that were for profit (adjusted odds ratio [OR], 1.09; 95% confidence interval [CI], 1.06-1.12); located in an urban area (OR, 1.14; 95% CI, 1.11-1.16); having more than 100 beds (OR, 1.04; 95% CI, 1.01-1.07); and lacking a special dementia care unit (OR, 1.11; 95% CI, 1.07-1.15) had a higher likelihood of having a feeding tube. Additionally, feeding tube use was more likely among residents living in facilities that had a smaller proportion of residents with do-not-resuscitate orders, had a higher prevalence of nonwhite residents, and lacked a nurse practitioner or physician assistant on staff. CONCLUSIONS: More than one third of severely cognitively impaired residents in US nursing homes have feeding tubes. Feeding tube use is independently associated with both the residents' clinical characteristics and the nursing homes' fiscal, organizational, and demographic features.

PMID: 12837714 [PubMed - indexed for MEDLINE]

67: JAMA. 2003 Jul 2;290(1):105.

Comment on:

JAMA. 2002 Nov 13;288(18):2324-31.

Alzheimer disease: "it's okay, mama, if you want to go, it's okay".

Markowitz AJ, Rabow MW.

Publication Types:

Comment

PMID: 12837718 [PubMed - indexed for MEDLINE]

68: Lancet. 2003 Apr 19;361(9366):1352-3.

Dutch television report stirs up euthanasia controversy.

van Kolfschooten F.

Publication Types:

News

PMID: 12711476 [PubMed - indexed for MEDLINE]

69: Leuk Res. 2003 Jun;27(6):481-8.

The final phase in acute myeloid leukaemia (AML). A study on bleeding, infection and pain.

Stalfelt AM, Brodin H, Pettersson S, Eklof A.

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To increase the knowledge of the final phase of acute myeloid leukaemia (AML) a retrospective review of the medical and nursing records of 106 adult patients with AML who had died in 1995-1997 was made. A total of 27 patients were treated with curative intent at the time of death and 79 patients were prescribed palliative care. From the documentation, an evaluation of the frequency and severity of bleeding and pain episodes was made during their last week in life, and the occurrence of infection criteria was studied. Notations on bleeding were found in 44%, infection in 71% and pain in 76% of the patients. In 54% of the morphine administration days, no information on the effect of given morphine treatment was registered. To give AML patients in the final phase, the best possible treatment, skills in palliative medicine and palliative care are important.

PMID: 12648506 [PubMed - indexed for MEDLINE]

70: Lung Cancer. 2003 Jul;41(1):113-20.

Radiographic images and the emergence of optimism about recovery in patients with small cell lung cancer: an ethnographic study.

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BACKGROUND: In a previous study, patients with small cell lung cancer showed "false optimism" about their recovery. Because patients' ideas about prognosis affect the choices they make regarding their treatment and end of life care, we explored the reasons why patients showed this optimism. **METHODS:** An ethnographic study was conducted involving 35 patients with small cell lung cancer in a lung diseases ward and outpatient clinic in a university hospital in the Netherlands. Patients were observed during their entire illness trajectory from diagnosis until death. **FINDINGS:** At the point of diagnosis, the patient felt ill but not to such a degree that a diagnosis of an incurable cancer was expected. The patient was convinced of really having a cancer when he could see "with his own eyes" a tumour on the radiographic images. During and just after chemotherapy treatment, the patient felt very ill, much more than at the time of diagnosis. It felt as if treatment had made things worse. The patient was convinced that he had been successful in his fight against the tumour when he could see "with his own eyes" a much smaller tumour on the radiographic images. **INTERPRETATION:** When there was a discrepancy between what patients felt and what the doctor said, radiographic images were used to convince the patient that the doctor was right. An effect of this practice is that patients "learn" to not trust their own bodily sensations and to consider clinical evidence as a more reliable source of information about their condition.

PMID: 12826320 [PubMed - in process]

71: Med J Aust. 2003 May 19;178(10):508-9.

Caring for the dying: the doctor as healer.

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Publication Types:

Review

Review Literature

PMID: 12741940 [PubMed - indexed for MEDLINE]

72: Med J Aust. 2003 Feb 17;178(4):171-4.

"Death talk": debating euthanasia and physician-assisted suicide in Australia.

Somerville MA.

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Imprecise language and deliberate confusion of important ethical and legal concepts are clouding our understanding of controversial end-of-life issues. This could affect our decision about whether or not to legalise euthanasia.

PMID: 12580745 [PubMed - indexed for MEDLINE]

73: Mt Sinai J Med. 2003 Mar;70(2):85-92.

Stability of preferences regarding life-sustaining treatment: a two-year prospective study of nursing home residents.

McParland E, Likourezos A, Chichin E, Castor T, Paris BE BE.

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BACKGROUND: The use of advance directives is based on the consensus that physicians should respect preferences expressed by competent patients about future treatments. Patient preferences are, however, subject to change and may be influenced by a number of factors. The purpose of our study was to evaluate the durability over time of decisions made regarding terminal care of mentally intact nursing home patients and the influence of such factors as intervening illness, loss of significant others, and cognitive, emotional and functional decline. **METHODS:** We undertook a longitudinal prospective cohort study in which 65 mentally competent nursing home patients were interviewed at three intervals (at baseline and after one and two years). For each patient, demographic,

medical and socioeconomic data were collected and assessment of mood, function, cognition and preference for life-sustaining therapies (including cardiopulmonary resuscitation and parenteral and enteral nutrition) was obtained. RESULTS: Preferences regarding cardiopulmonary resuscitation and parenteral and enteral nutrition changed over both the 12- and 24-month study periods. Only degree of change in cognitive status proved to be predictive of changes in decision. Gender, presence or absence of depression, change in level of functional abilities and intercurrent illness or stressor did not influence change regarding life-sustaining therapy. CONCLUSIONS: In light of our findings, we suggest that periodic re-evaluation of these advance directives be performed and that ongoing discussions be initiated with their patients by health care professionals.

PMID: 12634900 [PubMed - indexed for MEDLINE]

74: Nurs Ethics. 2003 May;10(3):236-7.

Medical technology, end-of-life care and nursing ethics.

Pang SM.

Publication Types:
Editorial

PMID: 12762458 [PubMed - indexed for MEDLINE]

75: Nurs Stand. 2003 May 7-13;17(34):20-1.

Laughing through the pain.

White F.

North London Hospice.

PMID: 12764970 [PubMed - indexed for MEDLINE]

76: Nurse Pract. 2003 May;28(5):38-47.

Advance directives: a guide for patient discussions.

Maxfield CL, Pohl JM, Colling K.

Minneapolis Cardiology Associates, Minneapolis, MN, USA.

Publication Types:
Review
Review, Tutorial

PMID: 12792267 [PubMed - indexed for MEDLINE]

77: Nurse Pract. 2003 May;28(5):11.

Why "techno-slang" at the end of life?

Pearson LJ.

Publication Types:
Editorial

PMID: 12792264 [PubMed - indexed for MEDLINE]

78: Qual Life Res. 2003;12 Suppl 1:91-4.

Quality of life and end-of-life decisionmaking.

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Since 1976, when the New Jersey Supreme Court decided the Karen Ann Quinlan case

(In re Quinlan, 355 A.2d 647 (NJ), 1976 cert. denied, 429 US 922, 1976), it has been apparent that the concept of quality of life is fundamental to end-of-life decisionmaking. Yet there has been a great deal of reluctance by courts--which have been the primary engine of lawmaking in end-of-life matters--to use this concept overtly.

Publication Types:
Legal Cases

PMID: 12803315 [PubMed - indexed for MEDLINE]

79: Resuscitation. 2003 Feb;56(2):159-65.

The influence of new guidelines on cardiopulmonary resuscitation (CPR) decisions. Five cycles of audit of a clerk proforma which included a resuscitation decision.

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Current guidelines advise discussion with patients before issuing a 'do not attempt resuscitation' (DNAR) order. We report five audit cycles of cardiopulmonary resuscitation (CPR) documentation after introducing a proforma,

the last cycle following the latest guidelines. In first audit data were collected from 75 patient discharges. CPR decisions were documented in 27 (36%). Four subsequent point prevalence audits carried out on all inpatients following proforma introduction showed documentation improved to 102/109 (94%), 135/148 (91%), 131/140 (94%) and 102/119 (86%) in cycles two, three, four and five, respectively. The last three audits also revealed that consultants consistently made more DNAR orders than trainee doctors. However, following the introduction of the latest guidelines the proportion of patients in whom a decision was made, and the percentage of those decisions that were DNAR, fell.

PMID: 12589989 [PubMed - indexed for MEDLINE]

80: Resuscitation. 2002 Dec;55(3):349.

Comment on:

Resuscitation. 2002 Aug;54(2):115-23.

DNAR policy in 88.5% of 1 023 patients dying in their hospital in 1999.

Steen PA.

Publication Types:

Comment

Letter

PMID: 12458075 [PubMed - indexed for MEDLINE]

81: Resuscitation. 2002 Dec;55(3):235-40.

Medical end-of-life decisions in Norway.

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AIM: Previous studies indicate that Norwegian physicians hold conservative attitudes towards ethically controversial end-of-life decisions. The present study was undertaken to explore whether in Norway euthanasia may be hidden under

labels such as death after analgesic injections and withholding or withdrawing treatment. METHODS: A postal questionnaire containing 76 questions on ethical, collegial and professional autonomy issues was sent to a representative sample of 1616 active physicians in Norway in 2000. RESULTS: 83% responded. A total of 8.1% had terminated life-prolonging treatment based on the resource situation, while 53.5 and 40.1% respectively had stopped life prolonging treatment due to the wish of the patient and the wish of the patient's relatives. Although not significantly, anaesthesiologists more often reported to have stopped treatment due to resource considerations. One percent of the physicians reported to have shortened a patient's life intentionally (other than stopping futile treatment). All of these were men. Logistic regression showed no effect when gender, age and

specialty were analysed simultaneously. 10.6%, and male more often than female physicians, had had experience of unintentional patient death in relation to pain treatment. Anaesthesiologists had had experiences of death following an analgesic injection no more than other specialists. CONCLUSIONS: Only a small minority of Norwegian physicians has committed euthanasia. However, patient death has occurred following ethically questionable decisions such as withdrawal of treatment based on resource considerations and requests from the family.

PMID: 12458059 [PubMed - indexed for MEDLINE]